CLINICAL ETHICS

A proposed rural healthcare ethics agenda

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J Med Ethics 2007;**33**:136–139. doi: 10.1136/jme.2006.015966

The unique context of the rural setting provides special challenges to furnishing ethical healthcare to its approximately 62 million inhabitants. Although rural communities are widely diverse, most have the following common features: limited economic resources, shared values, reduced health status, limited availability of and accessibility to healthcare services, overlapping professional–patient relationships and care giver stress. These rural features shape common healthcare ethical issues, including threats to confidentiality, boundary issues, professional–patient relationship and allocation of resources. To date, there exists a limited focus on rural healthcare ethics shown by the scarcity of rural healthcare ethics literature, rural ethics committees, rural focused ethics training and research on rural ethics issues. An interdisciplinary group of rural healthcare ethicists with backgrounds in medicine, nursing and philosophy was convened to explore the need for a rural healthcare ethics agenda. At the meeting, the Coalition for Rural Health Care Ethics agreed to a definition of rural healthcare ethics and a broad-ranging rural ethics agenda with the ultimate goal of enhancing the quality of patient care in rural America. The proposed agenda calls for increasing awareness and understanding of rural healthcare ethics through the development of evidence—informed, rural-attuned research, scholarship and education in collaboration with rural healthcare professionals, healthcare institutions and the diverse rural population.

Approximately 62 million people, roughly 20–23% of the population of the US, live in rural communities distributed over three quarters of our country's land mass.[1–4] Residents of rural regions are more likely to have chronic health problems and poorer health status than their urban counterparts. Access to care for rural residents is affected by shortages of clinicians, facilities and specialised services; sociocultural factors; as well as geographical and climatic barriers that affect travel conditions.[3 5–8] The burden of disease and disability for rural populations is considerable and places great demands on a resource-poor care system. For these reasons, rural residents are an underserved population. An appropriate standard of care for rural people has emerged as a critical concern in the national discussion of health disparities, leading in recent years to the development of federally qualified health centres and critical access hospitals.

With the increasing recognition of rural health disparities has come a growing awareness of the special ethical considerations inherent in healthcare in rural communities.[3 5 7–9] For example, ethically important aspects of care provision seem to be especially salient in relation to stigmatising illnesses, such as mental illnesses, substance misuse disorders and some infectious diseases.[3 9–11] Solutions to ethical issues in rural areas may differ from those derived in urban areas.[8 9 12 13] For instance, a clinician may be required to provide a family member or friend with mental or sexual healthcare in a rural setting, whereas the presence of alternative clinicians and facilities in urban areas may better permit role separation and clearer personal and professional boundaries.[3 8 11 14–16]

All clinicians and administrators are challenged by ethical issues that pose barriers to providing quality patient care. Responses to ethical issues are often based on the generally accepted ethical principles of respect for patient autonomy, confidentiality, fidelity and distributive justice. Often less recognised is how the context where the ethical conflict occurs can affect the application of ethical standards of practice. Rural clinicians and administrators may experience frustration with professional codes of ethics and ethical standards of practice that are primarily targeted toward resource-rich, less interdependent urban communities.[12 17–19] Furthermore, clinicians and administrators have limited access to ethics-focused resources, including ethics committees, ethics literature, trained ethics consultants and opportunities for ethics education.[9 13 17 19] Rurality needs to be understood as a setting culturally distinct from that which has been the primary focus of healthcare ethics—that is, the non-rural and large healthcare facility.[8 9 20]

RURAL HEALTHCARE CONTEXT

Rural communities are unique not just because of their small population density or distance from an urban setting, but also because of the combination of their social, economic and geographical characteristics as well as their residents' cultural, religious and personal values.[1 5 8 21–23] Some of the unique characteristics of the rural healthcare context include the following.

Limited economic resources

In general, rural populations have lower income per capita and higher poverty rates than urban populations.[6 8] Rural residents are also more likely to be underinsured or uninsured, further increasing the financial hardship of interacting with the healthcare system.[1]

Abbreviation: ASBH, American Society of Bioethics and Humanities

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Received 11 January 2006
Revised 11 January 2006
Accepted 13 April 2006

Reduced health status

Rural populations have a higher proportion of vulnerable residents, specifically adolescents and elderly people, who require more health services[24]; a higher probability of chronic or life-threatening disease[3]; higher infant mortality[25]; and a higher suicide rate than their urban counterparts.[26] Additionally, rural residents have distinctive mental health issues, including substance misuse and seasonal affective disorder,[1] and encounter a greater prevalence of environmental and occupational-related hazards.[3 6 8] A large study of US veterans living in rural settings showed that they had worse health-related quality of life scores than their urban counterparts.[27]

Limited availability of healthcare services

Fewer healthcare providers are available per capita for rural versus urban populations. Only 11% of doctors practise in rural America.[1 2] Limitations include the availability of doctors, nurses, social workers, dentists, home-based providers and mental health professionals. In particular, the availability of mental health services is limited for people living in rural communities.[1 6 8] Most areas that are short of health professionals are in the rural counties. Rural healthcare facilities generally are small and often provide a limited range of services.

Cultural and personal values

Cultural and personal values affect the recognition of illness, seeking healthcare, acceptance of and attitude towards care givers, perceptions of informed consent and decisions surrounding medical interventions. Several general values, particularly common in rural settings, that influence healthcare decision making are self-reliance and self-care, use of informal supports (ie, neighbours, family and church), a strong work ethic, and a different perception of health and illness (illness occurs when a person cannot work).[5]

Limited accessibility to healthcare services

Distance to and between healthcare professionals and facilities can be extensive, limiting their accessibility in rural settings.[5 28] Distance to such services can be additionally problematic because of the lack of public transportation, challenging roads, and environmental and climatic barriers such as oceans, mountain ranges or extreme weather conditions.[9] These obstacles often make transfer to urban care centres difficult or impossible. The patient may be reluctant to receive care in a ''far-away'', unfamiliar city. Patient reluctance is further exacerbated, knowing that one's family and friends will be less likely to provide support as a result of the distance.

Dual and overlapping professional–patient relationships

The geographical and social structure of rural communities creates multiple relationships between members of the community and healthcare providers.[5–8] Practising medicine in a small setting generally means living and working in the same place[29]—that is, being ''part of the community'', and can create both benefits and problems in patient care.[5 30] In the rural setting, there is little buffer between the provider, the hospital administrator and the patient.

Care giver stress

Care giver stress is common among rural healthcare providers owing to the combination of professional isolation, overlapping relationships, immense clinical responsibilities, and emotional and physical exhaustion.[3 8] The limited resources to help cope with such stress, coupled with the rural value of self-reliance, leads providers to either just accept the stress in a stoic manner or reach a point of burnout.

COMMON RURAL HEALTHCARE ISSUES

The unique characteristics of the rural setting shape and influence the frequency and the nature of specific ethical issues and also influence how healthcare professionals respond. Common ethical issues that are strongly influenced by the rural context include the following.

Confidentiality

Overlapping relationships between healthcare professionals, patients, families and community members make privacy difficult.[3 8 10 11 15–17 29–33] For instance, professionals may be reluctant to record in a patient's medical record a potentially stigmatising diagnosis, because it is not uncommon for a patient's relative or friend to be a member of the healthcare professional's staff or even the billing clerk who records diagnoses.

Truth telling

Despite the generally accepted ethical principle of truth-telling, the community or a patient's cultural values might suggest something other than full, open disclosure of information, raising distinctive ethical conflicts. For example, a community value might direct the doctor to not communicate ''bad news'', because it is perceived as eroding a patient's hope. Therefore, the clinician faces choosing between the traditional standard of healthcare ethics and going against the community norm.[7]

Shared decision making

In the rural context, healthcare professionals struggle with the decision of whether to disclose medical options that are not available or are routinely refused by rural patients, such as taking prohibitively expensive drugs or travelling hundreds of miles to a large city for a specific procedure. Ethical issues arise when patients insist that their provider make treatment decisions from them as the cultural norm encourages ''it's the doctor's decision''.[7]

Boundary issues and professional–patient relationship

Overlapping or multiple roles often lead to various relationships between clinicians and patients in rural settings, creating boundary-related ethical conflicts.[8 9 14 34–36] Such situations are challenging because they bring into play competing roles, values, duties and community expectations to the classic ethical understanding of the professional–patient relationship. Conflicts in mental healthcare, with its related stigma and interpersonal complexity, are compounded in a close-knit rural community.[15 37] Because multiple relationships are expected in rural communities, disengagement of the provider from multilevel relations may lead to a sense of rejection, a lack of trust and produce a less than productive clinical environment.

Cultural and personal values

Cultural and personal values exert greater influence on rural communities than urban healthcare because local customs and practices affect a greater proportion of patients in a care giver's practice. Ethical conflicts arise when there is insufficient recognition and respect for indigenous rural values or when the clinician overemphasises the values compromising the clinician's professional, established ethical standards or personal values.

Limited resources and access to quality care

Geographical isolation can force the provider to make decisions based more on clinical impression rather than the most up-to-date specialty knowledge and technology.[17 27 38 39] Some rural providers believe they compromise quality because of the need to practise outside their area of training. Although the literature reflects some variability about quality as an ethical conflict, the concern is shared by both doctors and nurses.[12 18 40]

Rural healthcare ethics agenda

- Develop an understanding of the concept and scope of rural healthcare ethics.
- Increase awareness and understanding of issues on rural healthcare ethics as perceived by rural residents and healthcare professionals, including the contextual influence on ethical issues and how the issues are different from non-rural settings.
- Increase awareness and understanding of rural healthcare ethics decision making, including how living and working in regionally diverse rural communities affects the response to ethical issues.
- Collaborate with rural healthcare professionals to draft guidelines for dealing with common, recurring ethical conflicts.
- Explore, assess and propose models for ''doing ethics'' in small rural health facilities.
- Develop and implement ethics training curriculums and other educational resources for and with rural clinicians, administrators and policy makers.
- Provide an ethics perspective to administrators and policy makers charged with allocating healthcare resources, supported by empirical data on potential urban–rural healthcare disparities.
- Foster a dialogue with the general healthcare ethics community regarding the unique nature of rural ethical issues.

Patient's inability to pay for care

Rural providers often encounter situations in which they have to decide whether or not to provide necessary care with little or no reimbursement, potentially jeopardising both the patient's health and the provider's overall practice.[9 12 41] Not providing the needed services is even more difficult when a provider encounters the patient or their family in the community.

Referral to large, specialised and distant medical centres

It is not uncommon for patients to resist or refuse transfer to urban secondary and tertiary care centres owing to mistrust or fear of the unfamiliar urban environment.[7] The provider is thus confronted with the conflict of how aggressively to persuade a patient to seek the needed treatment. If patients maintain their refusal of the referral, the clinician must suffer the burden of the patients' insistence on what the clinician believes is less than optimal care. The burden may be accentuated by legal or licensure issues when the professionals believe they are asked to practise outside, or potentially outside, their scope of competence.

Allocation of resources

Resource allocation is another growing conflict noted by rural doctors,[14 17 34] case managers,[38] nurses[18 42 43] and other administrators.[12] Providers must routinely allocate both time and treatment. As the rural population tends to be poorer, sicker and has access to fewer resources, allocation conflicts become routine for healthcare professionals and facilities.[44]

RURAL ETHICS RESOURCES

Despite the need, many rural facilities and professionals have limited access to ethics resources. A recent literature review found that between 1966 and 2004 only 55 publications specifically and substantively dealt with rural healthcare ethics. Of the 55 publications, 30 were clinically focused, 15 discussed organisational ethics and 10 discussed ethical ramifications of policy. Only seven were original research publications.[45]

An important ethics resource in healthcare facilities is an ethics committee. However, studies have suggested that differences exist between the availability, the frequency and the competency of rural ethics committees compared with urban committees. A survey of 117 hospital administrators from six western states of the US found that only 42% of the hospitals had ethics committees or other formal models for ethics services.[9 12] Many barriers contribute to the lack of existing or effective rural ethics committees, including the lack of ethics expertise, financial resources to support ethics training, time for training, a regulatory requirement and an appropriate model for ethics committees.[9 12 13 19 46–53] When rural providers did seek training or consulted the ethics literature, the training and material had such an urban focus that it proved unhelpful.[3]

There also seems to be a limited number of bioethicists working or living in rural communities determined by how American Society of Bioethics and Humanities (ASBH) members were distributed along a rural–urban continuum.[4] ASBH members were 10.7 times as likely to be represented in urban as in rural settings when compared with the general population, 25.6 times more so when hospital facilities were compared and 6.9 times more so when hospital beds were compared. Although not all bioethicists are ASBH members, these findings suggest that the availability of professional bioethical resources may be inadequate in rural America.

As a result of limited ethics committees at rural facilities, rural-focused ethics publications and professional bioethics resources, we see a need for increased rural healthcare ethics resources that integrate rural culture and values into ethical reflection and decision making.

CONCLUSION: A RURAL ETHICS AGENDA

To enhance the quality of healthcare in rural settings, we saw the need for a rural ethics agenda. The agenda grew from the recognition of several issues. Firstly, ethical issues are greatly influenced by contextual factors; the rural environment is one of those contexts, just as the urban setting is a unique setting.[54] Secondly, there exist only a few qualitative and quantitative studies focusing on the relationship between rural characteristics and healthcare ethics. Thirdly, there are limited rural focused ethics resources for the clinicians or administrators confronted with complex ethical issues. Fourthly, the development of rural ethics resources should be empirical, culturally attuned and drafted in collaboration with rural healthcare professionals.

In October 2004, an interdisciplinary group of US rural healthcare ethicists with backgrounds in medicine, nursing, religious studies and philosophy convened to explore the need and the content of a rural healthcare ethics agenda. The participants were selected based on their research and publications in rural ethics (by WN). The self-named ''Coalition for Rural Health Care Ethics'' agreed on a definition of rural healthcare ethics—to focus ethical reflection on healthcare-related issues in the distinct context of the rural setting. The group also discussed a broad-ranging rural ethics agenda with the ultimate goal of enhancing the quality of patient care in rural America. The proposed rural ethics agenda includes the following objectives.

Dealing with the proposed agenda will require the combined efforts of healthcare ethicists and researchers working in close collaboration with rural healthcare professionals and organisations. Despite the ambitious nature of the agenda, we believe there is a need to close the gap that places rural populations at

risk not only for clinically disparate care but also for ethically disparate care. As such, we propose the rural healthcare ethics agenda to help us move in the direction of narrowing the gap.

ACKNOWLEDGEMENTS

This work was supported by the Veterans' Rural Health Initiative, White River Junction, Vermont, USA.

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Competing interests: None.

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The views expressed in this article do not necessarily represent the views of the Department of Veterans Affairs or of the US government.

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